The National Patient Organization Dedicated to Advocacy, Education and Research for Primary Immunodeficiency Diseases

July 26, 2012

John Kromm
Office of Health Care Reform
Executive Department
State House
Annapolis, Maryland 21401

RE: Draft Analysis of Essential Health Benefits Benchmark Options

Dear Mr. Kromm,

The Immune Deficiency Foundation (IDF) appreciates the opportunity to comment on the draft analyses and reports for the Essential Health Benefits Advisory Committee. IDF, founded and headquartered in Maryland since 1980, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

Primary immunodeficiency diseases occur in persons born with an immune system that either is absent or hampered in its ability to function. While not contagious, these diseases are caused by hereditary or genetic defects and can affect anyone, regardless of age or sex. The World Health Organization recognizes more than 150 primary immunodeficiency diseases, which are a group of rare disorders. The treatment for many of these patients who are unable to produce enough antibodies (immunoglobulin) to fight viruses, bacteria and fungi is immunoglobulin replacement (Ig) therapy, where immunoglobulin, fractionated from human blood plasma, is infused into a patient’s body. This lifelong and lifesaving therapy allows most patients to live normal, healthy and productive lives.

As a patient organization representing patients who have rare and chronic diseases, we are very concerned that the draft analyses do not take into account persons with rare and chronic diseases. The highlighted documents and the benefits represent only the normal and standard benefits. Over 30 million persons in this country have a rare and chronic disease, accounting for nearly 10% of the U.S. population and should not be ignored.

We are extremely concerned with the inclusion of Coventry Health Care as a benchmark plan in the Options. Our patients’ experience with Coventry is abysmal. Their policies regarding Ig replacement therapy are the most regressive of any health insurer with whom we have ever had contact. They not only disregard the standards of care for patients with primary immunodeficiency diseases, their policies also place patients at serious health risks.

The report noted that Coventry Health Care had the “leanest benefits.” Unfortunately, these lean benefits ignore medical literature and expertise for treatment and result in inappropriate care for patients with primary immunodeficiency diseases. For Maryland to use Coventry Health Care as a benchmark is a threat to persons with rare and chronic disease, especially the primary immunodeficiency community. There are other plans that could be better used as benchmarks and we request that you eliminate the Coventry Health Care plan as an example.

Regarding the rest of the report, there is a total lack of recognition and disregard for rare and chronic diseases in the Benefit Differences by Benchmark Option chart. In Benefit 6e (Prescription drugs – Specialty Drugs), the small group, HMO and Federal plans all have checkmarks which mean “covered benefit, limits noted” yet there are no explanations to know what limits are noted and how. However, our experience with health plans has shown that some companies have specialty tiers that call for co-insurance requiring the patient to pay anywhere from 20% to 50% of the cost of their prescription drug. For persons who need a lifelong and lifesaving therapy that requires a drug such as immunoglobulin, a
co-insurance model is tantamount to a death sentence. Patients will not be able to afford their lifelong and lifesaving Ig replacement therapy. In such a situation, the benefit becomes a "hollow" benefit.

We have a further concern regarding whether or not only one immunoglobulin (Ig) product will be available to our patients rather than the number currently in the market. We must note that the various Ig products are neither interchangeable nor clinically equivalent according to the FDA. Our patients tolerate different Ig products differently. Medical evidence confirms that fact and the potential for serious adverse effects if patients are limited to only a certain brand is significantly large.

How will the State of Maryland assure its citizens that the benefits promised are “full” and not “hollow”? That question is not addressed.

In Benefit 9 (Preventive and wellness services and chronic disease management), the only chronic disease that is mentioned is diabetes, which is not a rare disease. All other categories mentioned are preventive and wellness categories. The state of Maryland should insist on knowing how insurers will address the chronic disease management of rare and chronic diseases as required by the Affordable Care Act (ACA).

We fully understand and appreciate the need for cost-efficient, qualified health plans. We also know the needs of our patients. Our concern is that health insurance policies that discourage the proper treatment of patients with primary immunodeficiency diseases may be imposed. If this happens, the health care system as a whole will ultimately suffer, as our patients will become constantly sick, use the ER multiple times per year, need several stays in the ICU, rely on multiple antibiotics, miss increasing number of days of work and eventually be officially labeled as disabled.

Please assure Marylanders with rare and chronic diseases that they will have the protections the Affordable Care Act meant them to have. Because Maryland is required to approve the benchmark plans in late September, we request a meeting as quickly as possible to discuss these issues in detail.

Thank you for your attention to this important issue.

Sincerely yours,

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